

## CHAPTER 2 DESIGN AND IMPLEMENTATION

### ISSUES IN RESEARCH WITH PERSONS WITH DEVELOPMENTAL DISABILITIES

*The JLS multi-method approach enables us to address practical issues in data collection.*

This chapter briefly reviews several issues involved in doing research with people with developmental disabilities and how, in JRB Associates' use of a *multi-method approach*, we have attempted to address these issues within the context of the transition of *Jackson* clients from institutional to community living environments. Many of the practical issues related to developing the initial design and conducting the survey in the institutions are only summarized here; they were treated more fully in the *Year 1 Report*. Instead, the discussion of implementation issues focuses principally on our visits with individuals in the community.

#### Communication

As noted in Chapter 1, the *Jackson* Longitudinal Study (JLS) goes beyond earlier efforts in seeking the input of the clients themselves regarding their level of satisfaction about their living environments and their sense of well-being. Although the importance of doing this has been recognized at least since the Pennhurst longitudinal study (begun in 1980)<sup>1</sup>, methodological problems have prevented most researchers from doing so consistently. For instance, in the Pennhurst study, the only persons interviewed were those known beforehand to be able to respond to a verbal interview, even though the researchers knew that about half the residents were nearly or completely non-verbal.<sup>2</sup>

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*This approach lets us gather data from persons who would otherwise not be able to be represented in the study.*

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Our approach is somewhat different. First, where the person is partially or completely non-verbal, we *interview* the person and a "helper" together, allowing the person to respond to the extent he or she is able, and the helper to "speak for" the person when the person cannot or will not do so. (This is further discussed in the section "Using the Helper as Proxy for the Mover," below.) Second, we *observe* the person in his or her own living environment, taking note of behavior and conditions which can be compared to observations made earlier or later in the study, providing indirect evidence of changes in quality of life.

#### Consistency

Research has suggested that some people with developmental disabilities respond inconsistently to interview questions. For instance, given a choice among three alternatives, some may choose the last one offered - echoing the interviewer's last statement ("echolalic" response); some may always answer "yes" when a yes-

***The multi-method approach provides internal checks on the consistency of our data.***

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or-no response is asked for. Such problems could seriously affect data reliability.

Our interview design anticipates this possibility. In the interview process we do this in three ways. First, we make questions as "concrete" as possible. Second, the instrument asks similar questions in a number of different ways, requiring different types of responses. Third, we encourage our interviewer-observers to rephrase questions and to probe where a vague response has been offered.

Beyond these techniques, of course, stand the other data-gathering modalities mentioned above: the presence of the person's helper in the interview situation, and observation of the person in his or her living environment. We believe that by using all these methods, we have developed a system which provides adequate safeguards against possible distortion of the data.

Consent and  
Respect for the  
Individual

***We sought consent to participate in the JLS from each individual and from a parent or guardian.***

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Our effort to measure changes in individual *Jackson* class members' quality of life (QoL) necessarily involves direct contact with the people affected. It thus raises issues of respect for their rights and privacy, as well as questions of whether the interview process itself could possibly have damaging effects on a person's health or psychological wellbeing.

We determined that where a person could give consent directly to participate in the study, we should ask for consent and not proceed if the person was unwilling to be interviewed. Beyond that, we decided that it would be appropriate to obtain the permission of every *Jackson* client's parent(s) or legal guardian before including that person in our study. In a limited number of very clear-cut cases, we decided that it would be appropriate to go ahead with interview visits without obtaining guardian consent when clients agreed on their own to participate. Our decisions on this matter influenced the JLS design as well. We determined to interview and observe only a "stratified, representative sample" of the population within the institutions in part because we suspected that it would be difficult to obtain guardian permission to visit every mover prior to the time of the person's transition to the community. (This proved to be correct.)

Our caution on this issue stems primarily from our concern for the privacy rights of *Jackson* clients and the ethical implications of studies involving people with developmental disabilities. As the Pennhurst researchers noted in 1985, "[I]n past years, people living in institutional settings have been part of studies that would never been approved if the subjects had not been labeled mentally retarded."<sup>3</sup>

In addition, we were anxious to contact parents and guardians and explain the study to them. We recognized that the climate created by court-mandated deinstitutionalization was litigious, and we wanted to allay any suspicions that our study was inherently biased in favor of one position with regard to the question of community placement.

## SAMPLING THE JACKSON POPULATION

Our research design is based on a "pre-test post-test" model. The pre-test involved interview-observation visits with a *sample* of the *Jackson* population while they were still residents at Los Lunas and Fort Stanton. The post-test involved subsequent interview visits with all (or as many as possible) of the *Jackson* class members after they had moved into a community living arrangement in New Mexico. The same questions are asked and the same types of observations are made during the pre-move and the post-placement visits.

*Issues of timing dictated our decision to sample the pre-move population.* Why did we decide to select a sample of *Jackson* clients to visit before they moved? Why not interview everyone? Several considerations were at work. One was simply timing. During the first three months of the project it was necessary to construct and test the instruments and obtain guardian permission to begin the visits in the institutions. By then, several individuals had already moved. Second, we expected that early movers would be likely to be higher functioning individuals with fewer needs for supports in their new homes in the community. If so, the most reliable way to discover the "pre-moving" levels of satisfaction and quality of life of the *Jackson* class as a whole would be to visit a *representative cross-section* of the entire population in the institutions. To do this we constructed a "stratified, representative sample" consisting of people scheduled to move after May 1, 1993 (our target date for beginning the survey). We decided to visit each of them in approximately the order in which they were scheduled to move, depending also on whether we were able to obtain guardian consent. (Characteristics of the population and the basis for choosing the sample are discussed in Chapter 3.)

## USING THE HELPER AS PROXY FOR THE MOVER

We first learned about the "helpers" assigned to *Jackson* class clients in the institutions from the *Jackson Management Manual*, after the JLS contract had been awarded in January 1993. Once an individual had been recommended for community placement, a helper - identified as "the person most capable of assisting the individual to understand and communicate throughout the process"<sup>4</sup> - was made a member of the individual's Transition Interdisciplinary Team (TIDT).

The idea of involving the individual's helper in our interviews was suggested as we were building the research design. Interviewer-

*Using the helper as "proxy" requires us to remember that no one can fully speak for another.*

observers were instructed to seek helper responses when the individual being interviewed was unable to provide an understandable response to a question. The individual usually remained present for all or part of the interview. The interviewer-observer instructed helpers participating in the interview to put themselves as nearly as possible into the position of the individual as they answer questions. As the helper (as "proxy") responded to questions, the interviewer-observer monitored the quality of the interaction between that person and the individual, checking to see whether the individual exhibited any behavior that suggested disagreement with a response from the helper.

Despite these attempts to approximate the notion of the helper as "proxy" for the individual, we are aware that no one is able to speak totally for another, and that there may be considerable variance between proxy-answered interviews and those in which individuals answer for themselves. We therefore coded interview instruments as answered by the individual, by the individual with less than 50% "proxy" help, by the proxy with less than 50% input by the individual, and by the proxy alone. This enabled us to test for the significance of differences between data obtained from *Jackson* class members and from helpers.

## DEVELOPING AND TESTING THE INSTRUMENTS

*The DDPC's Quality Assurance Task Force provided the basis for our efforts to measure Quality of Life.*

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*The JLS Working Group and members of People First critiqued and helped to pre-test our instruments.*

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The dimensions of consumer satisfaction and Quality of Life that formed the basis for the *Jackson* Longitudinal Study stemmed from the Final Report of the Quality Assurance Task Force.<sup>5</sup> Our interview questions and observational guides were drawn largely from prior work in other states, including the Pennhurst Longitudinal Study referred to above. A list of references used in developing the instruments is found in Appendix C to the *Year 1 Report*.

As already suggested in Chapter 1, the concept of Quality of Life is necessarily subjective. Establishing and consulting the JLS Working group helped greatly in dealing with this reality. Three meetings of the group were held during the first three months of 1993 as we developed the instruments. Members raised concerns about an individual would communicate with the interviewer and about the subjectivity of the interviewer's understanding of the individual's perceptions. These discussions helped us to make our questions more concrete. The Working Group also endorsed the idea of using "proxy" responses from the individual's helper where needed. Two representatives of the self-advocacy group People First were members of the Working Group. They allowed us to "pre-test" some of the interview questions with members of People First at one of their meetings, and then provided helpful feedback about the interview process, the questions and the way they were phrased.

The observation element of our multi-method approach grew in significance as we learned more about the difficulties we would have in gathering data through face-to-face interviews with *Jackson* class members. The Working Group helped us define our observational indicators more precisely and operationally, which resulted in our developing a separate instrument for recording observation data.

## CONDUCTING THE INTERVIEW-OBSERVATION VISITS

### Staff

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*Our Senior Research Associate anchors the field research team.*

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In our first year, JRB Associates engaged the services of a Senior Research Associate (SRA), a highly qualified counseling psychologist who has considerable experience working with people with developmental disabilities. She was involved in the latter stages of development of the interview and observation instruments, and conducted all of the Year 1 interview-observation visits. Having one person make all the visits provided the advantage of eliminating for the first year the problem of "inter-coder reliability." For subsequent years this problem has been mitigated by having the SRA - based on her experience during the first year - develop a detailed set of interview and observation guidelines and assist in providing training for additional Research Associates brought onto the JLS team in Year 2.

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*Selecting qualified research associates and training them to assure consistency has been important.*

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Because of increased workload and geographical factors, at the start of Year 2 JRB Associates hired two additional Research Associates (RA) under contract to undertake interview-observation visits with *Jackson* clients who have moved to communities in the north/west and south/east parts of the state. Although more than half of the movers in the study reside in the Albuquerque metropolitan area, the remainder live in widely scattered sites all over New Mexico. The RAs have extensive backgrounds in counseling (one in clinical psychology) and in working with individuals with developmental disabilities. They underwent two days of training with JRB Associates' evaluation specialist and the SRA, which included observing a visit and then conducting actual interviews and observations under her guidance.<sup>6</sup>

### Visits in the Institutions

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*A baseline sample of sixty individuals received visits in the institutions during the first two years.*

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During Year 1 the SRA conducted interview-observation visits with 32 individuals prior to their moving from Los Lunas and Fort Stanton. (We designated these pre-move visits as "baseline" or "T<sub>0</sub>" data.) An additional 28 T<sub>0</sub> visits were conducted in Year 2. The procedures used in arranging and conducting these visits established the pattern for later visits with individuals in the community.

First it was necessary enlist the cooperation of the institution's administration. *Jackson* transition coordinators were critical to the process by arranging for time, location and the presence of each individual's helper for each appointment. The interviewer-observer

*Procedures for the visits were designed to build trust, as well as to gather data.*

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### Visits in the Community

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*The first visit was made only after the individual had had time to settle into his or her new home.*

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*Research associates must be flexible in arranging for visits, to work around less predictable schedules.*

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assumed responsibility for determining the order of visit activities. She established a pattern of asking the individual early on to show her where he/she lived. This informal "tour" of the resident's living environment enabled her to establish an informal relationship with the individual and the helper, as well as to observe and gather data about the individual's "home" (usually the room), which she would later record.

She began each visit by explaining who she is. She described the JLS as an effort to find out how individuals' lives are affected by the transition. She stressed that the study is not part of the legal process, and that she is not a state employee. She emphasized that the interview is confidential and that they could say whatever they want to. If possible she obtained the individual's affirmative consent. Interviews are held where individual wants to be. At the close of the interview she briefly reviewed the individual's case file in conjunction with taking time to record her observations. She checked for consistency between what she had been told by the individual and staff and the documentation in the person's Individual Program Plan goals and objectives, activity log, incident reporting, etc. Before leaving, she mentioned that she or someone else on our team (depending on where the individual moves) would visit the person each year during the next 4 years.

Visits with individuals in the community are always made at the resident's home (rather than at work or training), since we have chosen in this study to focus primarily on the home environment. The first visit (called "T<sub>1</sub>") was not scheduled until the person had been living in the community for at least four months. This allowed time for the individual to settle in and for the formal transition process to be completed. In cases where the individual moved again prior to our T<sub>1</sub> visit, we waited until four months after that move before conducting the visit. The next visit, T<sub>2</sub>, was conducted close to the first anniversary date of the individual's move, and subsequent visits occurred annually (T<sub>3</sub> at the second anniversary, T<sub>4</sub> at the third anniversary, etc.).

The procedure for T<sub>1</sub> and subsequent visits was patterned on that described above for the T<sub>0</sub> visit with the sample in the institutions. However, a great deal of flexibility was required in adapting to the variations in community residential settings. Here the RAs had far less control of the environment - the time of day the visit could be made, interruptions by other clients or visitors, variations in routine, etc. Community living is often less predictable than life in the institution. Since the study design called for visits to *all* of the initial Jackson class members living in New Mexico for whom we had guardian consent, T<sub>1</sub> was often their first contact with the JLS team.

*High staff turnover  
requires us to re-explain  
the study constantly.*

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## Helpers in the Community

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*High staff turnover  
in the community-  
based  
homes complicated the  
question of whether a  
"helper" can act as a  
reliable "proxy."*

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*However, a consistent  
pattern of findings  
from several sources  
provides reassurance  
about the reliability of  
our data.*

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Moreover, because of high rates of residential staff turnover, even subsequent visits required the RAs to explain the study and often overcome initial resistance in order to gain the cooperation of provider staff.

Because there was no central staff as in the institutions, the RA was responsible for arranging visits on an individual basis. This was usually done at the time of initial telephone contact with someone at the individual's home, by asking, "Who knows the person best in his/her living environment?" Besides identifying an appropriate person who could act as a proxy, JLS interviewer-observers tried to determine the best time of day to conduct the visit, taking into account the individual's day program schedule and energy level, and when the helper could be present.<sup>7</sup>

Even for the To visits in the institution, it sometimes proved impossible for the individual's *helper* (i.e., the person so identified as a member of the individual's TIDT) to be present for the JLS visit, and another staff member who knew the individual frequently substituted for the helper. This was unavoidable, and contributed to uncertainty about the reliability of proxy-supplied data. On the other hand, even the *designated helper* was often someone not in the individual's everyday environment (not front line staff in a cottage).

Once the individual has moved into a community living arrangement and his or her TIDT is dissolved, the matter of who could act in the "proxy" role was further muddled. Residential provider staff tend to change often, and often at T1 the individual's "helper" had known the client for four months or less. Even at T<sub>2</sub> and later visits, staff or provider changes meant that the helper was often someone relatively new. When the helper had to act as the client's proxy in answering interview questions. The basis for those answers was not experientially very deep, and there could conceivably be quite a bit of variance in the data supplied, depending on the helper's prior experience, familiarity with the mover, level of education, etc.

In light of these highly variable factors, it has been encouraging to discover that when data on specific individuals are followed from T<sub>0</sub> through T<sub>5</sub>, a consistent pattern of findings about the direction of an individual's development tends to emerge. With this final report we resume our practice of using individual case histories to illustrate our findings. We also look more analytically at the patterns that emerge from the survey data. In Chapter 3 we report on our findings from the interview and observation visits. The case studies are presented in chapter 4. Chapter 5 summarizes the conclusions we have been able to reach about the outcomes of the *Jackson* transition process as a result of our five years of research.

NOTES TO CHAPTER 2

Conroy, J.W., & Bradley, V.J. 1985). *The Pennhurst Longitudinal Study: A report of five years of research and analysis*. Philadelphia: Temple University Developmental Disabilities Research Center. Boston: Human Services Research Institute.

<sup>2</sup> *Ibid.*: 119-120.

<sup>3</sup> *Ibid.*: 121.

<sup>4</sup> Rucker, L. *et al.* (1991, September 27). *The Jackson Management Manual*. Santa Fe: prepared for the State of New Mexico Department of Health and Human Services Department. Appendix A:2.

New Mexico Developmental Disabilities Planning Council Quality Assurance Task Force (1992, August 31). "Quality Assurance: Framework for Excellence" (unpublished MS). Santa Fe: State of New Mexico.

One additional RA candidate received initial and follow-up training but withdrew after review of two sets of his initial efforts indicated that he was having problems being sufficiently "objective" and non-judgmental in obtaining interview and observation data in the field. His experience illustrates the difficulty of gathering valid qualitative data in emotion-laden circumstances and ensuring inter-coder reliability.

One variable we have not found possible to control in the visit schedule is that the two newer research associates have schedules which permit them to visit the clients only on weekends. Often this means doing without the presence of staff who "know them best."